Available online at www.sciencedirect.com

SciVerse ScienceDirect

Procedia - Social and Behavioral Sciences 69 (2012) 467 – 476

Procedia
Social and Behavioral Sciences

International Conference on Education and Educational Psychology (ICEEPSY 2012)

Family caring for a family member with severe disability as a specific group of clients of helping professions

Jan Michalík*, Milan Valenta

Insitute of special needs pedagogical studies, Faculty of Education, Palacky University in Olomouc, Žižkovo nám. 5, Olomouc 77140, Czech Republic

Abstract

The success of educational and social services for caregivers is significantly influenced by the situation in the family – macro-social indicators or psycho-social nature of family members.
In 2010 and 2011 a research that mapped the situation in the mentioned families was conducted in CR. The caregivers' results were compared with intact population. The results confirmed that statistically significant differences in the answers of respondents from both groups related to the life quality factors and were proved in the overall majority of monitored markers.
The results are presented with the aim to focus on the areas applicable in the work of helping professions.

Keywords:
education, social services, helping profession, quality of life, care, disability, public support

INTRODUCTION

The presented results are a part of an extensive research of the quality of life of persons caring for a family member with disability that was conducted in the CR in years 2009-2011as a part of a research supported by the Czech Grant Agency (The quality of life of persons caring for a family memeber with severe disability 406/09/0177).
The percentage of the health disabled in individual countries in EU is stated from 5% to 19 %. However, practically it concerns not such a great difference in real numbers of the health disabled, but different criteria during assessment. Approximately 44,6 million people between 16 to 64 are considered as persons with long-term health problems or health disability, which

doi:10.1016/j.sbspro.2012.11.435

represents app. 16% of inhabitants in productive age in EU.[1]
Usually, there is two or three times as many persons who are „affected“ by impacts of health disability and its consequent care needs in the nuclear family. These persons, in various cases and various criteria, are also becoming subjects of interest of the so called helping professions. In 2004 more than 8 million people was employed in the sector of providing services to disabled persons and registered turnover of app. 868 million EURO in EU 27 while these numbers are expected to grow.[2]
Severe health disability is one of the most serious social events in current developed countries. It directly influences life (its quality) of a person who is a carrier of health disability and in various extent also close family members. The system of care for the disabled has a different standard in different countries. Their common characteristic (we speak about a few tens of the so called developed countries) is that public systems of support are realized by workers of professions that we got used to call helping professions. They mainly include medical staff, teachers, social workers etc. Less attention is paid to the position of caregivers.
In CR an extensive research focused on the quality of life of persons caring for a family member with health disability supported by GACR CR (project No. 406/09/0177) was conducted in years 2009 – 2011. The submitted article is one of the results of this grant's task.

1) Goals, methods and population research

The point and the main goal of the project was to set basal psycho-social markers determining the quality of life of persons caring for a family member with rare disease and describe phenomena chracterizing the concept of understanding the term *quality of life* of representives of the target group. (Next, compare this concept with how the term is understood by the intact population). Consequently, discriminate different features of the concept of the quality of life of people in the target group and on their basis prepare general methodology that could be used in other researches during determining markers connected with understanding and perceiving the content of the term *quality of life* of the target group. On the basis of results of such realized quantitative research key changes in value and psycho-social dispositions of probands (caregivers) were defined, monitored and analyzed.

Population groups in research
Group of caregivers
Research population was chosen from the basic population of persons caring for a person with severe health diability on the territiry of the whole CR. For the purposes of the given research the severe health disability was defined as a disability that corresponds with classification level „strong dependency“ and „total dependency“ (level III and IV) on the care according to classification system arising from the law about social services in CR.[3] It concerns people who out of 18 tasks regarding care for themselves (e.g. prepare meals, wash their bodies, get up from

[1] Deliverance of the Board to the Council, European parliament, European economic and social committee and committee of regions „ Position of the disabled in the broadened European Union: European plan of action 2006 – 2007 from 28.11.2005.
[2] Deliverance of the Board to the Council, European parliament, European economic and social committee and committee of regions „Position of the disabled in EU: European plan of action 2008–2009“ {SEC(2007)1548}
[3] Law No. 108/2006 Coll. about social services

bed, go upstairs) and out of 18 tasks of self-reliance (communication, money handling, clothes mending) do not manage in III. level 24 and in IV. level of dependency on care 31 tasks. Then it is possible to declare them as persons with severe disability.[4]
The total of 1 106 questionnaires were distributed by workers in social departments in municipal authorities of municipalities with extended authority. In the given period – till the end of March 2010, 519 legally filled in questionnaires returned.
Such composition of respondents was reached that it confirmed a highly stratified (partially also proportional) selection.

Control group persons
If in case of the caregivers a high level of territorial representativeness was reached, then in case of the control group respondents' selections it was different regarding the extent of procuring and logically the researched sample far less represents opinions of the basic group of persons. Nonetheless, we believe that the obtained results from the control group (see further) are sufficient for conducting a meaningful comparison. Participant were chosen randomly from students of the combined form of studying at UP in Olomouc. The characteristic of the basic sample of the control group in general features (see further) corresponded with caregivers regarding the sex of respondents (women prevailed). Distribution of the measuring tool was carried out in September and October 2011.
The basic requirement on the research participants was formulated this way: a person that cares for a child in a household (family), but does not care for any family member with severe disability at the same time. The addressed persons were students from the total number of app. 510 from whom, however, persons without children did not take part in filling out. Thus, in total 305 questionnaires was evaluated from the respondents of the control group.

Tab. No. 2 Characteristics of respondents of the researched groups

CAREGIVERS	CONTROL GROUP
SEX OF RESPONDENTS	
440 women (85%), 77 men (15), 0 persons (0%) did not fill in sex.	259 women (85%), 39 men (13%), 7 persons (2%) did not fill in sex.
THE MOST CARING PERSON IN FAMILY	
Women: 65,51 %, Men: 8,29%, Take turns: 16,8%, Did not respond: 9,4%.	Women: 137 (45%). Men: 4 (2%). Take turns: 111 persons (36%). Did not respond: 53 persons (17%).
LENGTH OF CARE FOR FAMILY MEMBER	
up to 5 years: 151 persons (29,1%), up to 15 years: 213 persons (41%), up to 25 years: 102 persons (19,7%), over 25 years: 46 persons (8,9 %), Did not respond: 7 persons (1,3 %).	more than 10 years: 62% less than 10 years: 30% Did not respond: 8 %
AGE OF RESPONDENTS	
up to 30 years: 11 persons (2,1%), up to 50 years: 242 persons (46,6%),	up to 30 years: 55 persons (18%), up to 50 years: 231 persons(76%),

[4] Dividing to to four levels correspond to methodology brought by the International Classification of Functioning, Disability and Health (ICF), WHO. available on http://www.who.int/classifications/icf/en/

up to 70 years: 226 persons (43,5%), over 70 years: 38 persons (7,3%) Did not respond: 2 persons (0,4%).	up to 70 years:11 persons (4%), Did not respond: 8 persons (2%).
EMPLOYMENT	
Full-time: 77 persons (14,8%), Part-time: 46 persons (8,9%) Without employment: 383 persons (73,8%), Did not respond: 13 persons (2,5%).	Full-time: 276 persons (90%), Part-time: 8 persons (3%), Without employment: 18 persons (6%), Did not respond: 3 persons (1%).
FAMILY STATUS	
Single: 36 persons (6,9%), Married: 399 persons (76,9%), Divorced: 65 persons (12,5%), Did not respond: 19 persons (3,66%).	Single: 27 persons (9%), Married: 247 persons (81%), Divorced: 23 persons (8%), Did not respond: 8 respondents (2%).

Study methodology

Researchers chose quantitative methodology based on the choice of a highly representative sample of probands, questionnaire research and statistical processing of data with classification of the first and the second level and determining statistical importance of the collected data (chí-quadrate – Pearson´s coefficient).

The measuring was delivered by a multi-level anonymous questionnaire with rating scales and standardized SEIQoL methodology. The used measuring tool was designed by the authors of the research on the basis of critical analysis and comparison of questionnaires used abroad (HRQoL – WHOQOL-BREF, SF-36) and experience of the main researcher of the grant scheme (i.e. direct parental experience). The questionnaire included, except for demographic items, 55 items grouped to ten parts based on their nature. The groups of items were oriented on assessing changes that occured in concrete time period in the past, assessing current situation and feelings and attitudes towards the future following the aspects related to health (e.g. number of visit at the doctor during the last half a year), psychological aspects (optimism, hopelessness…), social aspects (free time…), partner and family aspects (number of sexual intercourses, relationship stability…) economic and spiritual aspects (faith practice).

Questionnaire levels:

- part I. – General demographic and statistic data about respondents
- part II. A – general socio-psychological mood of respondents
- part II. B – existence of negative socio-psychological conditions of respondents
- part II. C – opinions of respondents in the area of external relationships
- part II. D – partner and family life of respondents
- part II. E – opinions of respondents on need of support extent in selected areas
- part II. F – general data about life of respondents and caring families
- part II. G – summarizing general opinion attitudes of respondents (the biggest gain, loss,feeling of happiness and atitudes to the future) in relation to care

2. Assessment of selected elements of psycho-spiritual nature of respondents

The monitored items in this part were not focused on facts and reality, but opinions, attitudes and assessment of respondents to selected questions of their lives. For those concerned these items have their origins or impacts in the long-term care for a family member with a severe disability. It referred to general and positively received personality values that on the one hand are „attributed" to caregivers from the perspective of the majority society, on the other hand due to the long-term care modification in their perception may occur by a caregiver. Respondents answered the question: „I assume that during my care the level of my *altruism (and other items)* has increased - did not change - decreased."

Tab. No. 3 Assessment of selected elements of psycho-spiritual nature of respondents

Monitored factor/frequency	Increased		Did not change		Decreased	
	Caregiver	Control	Caregiver	Control	Caregiver	Control
Change in the degree of altruism	52%	60%	41%	33%	4%	6%
Change in the degree of calmness and mental balance	18%	37%	31%	32%	48%	30%
Change in life optimism	12%	28%	41%	47%	43%	24%
Change in spirituality level	22%	34%	59%	53%	13%	11%

Comment:

Change in the degree of altruism of respondents

By altruism we understand attitudes and acting that concerns the welfare of others, charity, unselfishness, human sociality or the ability to cooperate. It is a feature that is usually perceived by population as an immanent part or guide through situations as „home care", „care for the sick", „care for the disabled" etc.

There is a simple assumption that the long-term care for a family member with disability necessarily brings along the increased level of understanding and the ability to identify with problems of others with the following imperative of help and care. However, in this sense research results showed higher number of respondents from control group who noticed increase in their altruism (60%) in contrast to to the group of caregivers (50%). It is possible to interpret the results referring to the higher age of carring respondents when their real ability (do not confuse with readiness) to help other people has decreased due to age – and mainly due to their provided care for a close person. On the contrary, the high percentage of respondents of control group who assess their readiness to help other people positively can be attributed to the fact that these respondents prepared professionaly for the position of the so called helping profession and therefore they could reflect in their answers their professional attitudes (or supposed readiness).

Change in the degree of calmness and mental balance of respondents

The opinion of respondents of our research showed that in the group of caregivers only 17,53% of respondents suppose that this ability or state of theirs has increased in the course of the care period. About a third of respondents 31,21% suppose that the ability remained the same and full 47,59% admit the level of their calmness and mental balance and the level of their ability to experience the feeling of calmness and mental balance has decreased during the care.

Thus, a well-known fact was confirmed that mental balance of human psyche and its ability to face chalanges that the care for a family member with disability brings along with the longer time of care decrease. The item confirming that this feeling/ state remained the same records comparable values with respondents from the control group (32,46%) as well as the caregivers (31,21%). However, where there has been a decrease in the feeling/state in caregivers, there has been an increase in the control group (37,05%).

Change in life optimism of respondents

Facing some facts that severe diability as well as the care for persons with severe disability brings, it is very difficult to keep life optimism and the so called positive expectations. On the contrary, it is possible to expect that persons „caring only for their own (healthy) child" shall show significantly more positive values in this item.

Caregivers (11,75%) in our research state that the level of life optimism has increased during the care. 41% of respondents state that it remained the same and full 43,35% - the largest group of respondents states that the level of their life optimism has decreased during the care.

27,5% of respondents in the control group (more than double the caregivers) notice an increase in life optimism, almost half of them assess this feeling as the same during the last five years and the decrease in the „feeling of optimism" noticed only one fifth of respondents.

It was confirmed that homecare for a family member with severe diability significantly correlates with the feeling of optimism of caregivers.

Change in the level of spirituality of respondents

This item monitored the increase or decrease of the ability and readiness of respondents to perceive the spiritual aspects of life – here e.g. regarding faith. It showed that overwhelming majority of respondents – almost 59% of caregivers and 53% of respondents from the control group – assess their situation in this area as „remained the same".

Only 22% of caregivers state that it has increased. However, this fact is stated by more than a third (34%) of respondents from the control group. It was noted that this item remained without answer by the relatively highest number of persons. It is literally stated that terms „faith and a believer" were not subjects of the research and therefore the information about „how many persons in the group were believers" cannot be deduced from answers!

Summary:

Firstly, it is necessary to state for this part that statistically important differences in the answers of respondents in all monitored items on the level of significance 0,05 were confirmed and three out of four also on the level of significance 0,01 (change in altruism and faith in human solidarity). The block of answers mapping the psycho-spiritual nature of respondents in relation to (the course) the care for a family member showed that caregivers showed far higher level of „soberness" while assessing the submitted items. It is necessary to mention that in the area of psycho-spiritual nature of respondents the control group shows a far higher level of „openness" and „content expectaion" towards the influences affecting them and in the statistically significant number of cases the increase in the values of the here monitored items was noticed.

Results

Tab. No. 4 Data's significance chart

Question	χ^2	SV	$\chi_{krit\ 0,05}$	Significance difference 0,05	$\chi_{krit\ 0,01}$	Significance difference 0,01
Altruism change	**7,916526**	**2**	5,991476	YES	9,210351	NO
Calmness and mental balance change	**43,8911**	**2**	5,991476	YES	9,210351	YES
Change in life optimism	**47,675**	**2**	5,991476	YES	9,210351	YES
Change in spirituality	**11,31256**	**2**	5,991476	YES	9,210351	YES

II. Arrival and existence of stress factors

In this part of the questionnaire the items were to confirm or disprove if negative changes in socio-psychological stability of ceragivers occur as a result of impacts accompanying the long-term care for a person with a severe disability or more precisely if such changes have not occured yet. It concerned answers to the question, „ State whether you have lately noticed the following states or feelings“, with the selection of answers „very often“, „often“, „rarely“ or „not at all“.

Tab. No. 5 Changes in socio-psychological stability of respondents

Monitored factor/frequency	Very often - often		Rarely		Not at all	
	Caregiver	Control	Caregiver	Control	Caregiver	Control
Massive arrival of depression and hopelessness	35%	16 %	41%	45 %	20%	39 %
Feeling of exhaustion	71%	54 %	24%	41 %	3%	5 %
Loss of the ability to enjoy free time	72%	33 %	23%	41 %	12%	26 %
Feeling of losing personal prospects	54%	17 %	27%	47 %	15%	36 %

Comments:

Massive arrival of depression and hopelessness

The adjective „massive“ was deliberately chosen in this item to insinuate to respondents that the question is not directed at common problems that from time to time occur to all people.
We state statistically significant differences in answers from both groups of respondents. If the caregivers observe the existence of this negative psychic state very often 11% and often 24%, then persons from the control group observe these states only in 3% of cases and often in 12% of cases. Also the possibility that excludes the existence (of arrival) of these conditions chose almost 38% of respondents from control group, but only 20% caregivers. The statement that the massive arrival of hopelessness is observed only rarely chose 40% caregivers and 45% persons from control group. Thus, the modus value is the same in both groups.

The feeling of exhaustion of respondents

Including this item came from general ascertainment of a huge strenuousness of the care for a person with severe disability. Impacts on the psyche and the structure of personality of an

individual are not only in the area of socio-psychological experiencing of the event, but also in the area of soma-psychological and biological when we simply talk about exhaustion arising from the long-term care.
Out of all items so far this item was „the most vigorously" responded to by respondents. The feeling of exhaustion is experienced „very often" by more than a quarter of caregivers (27%). Another 43% is „often" exhausted. 24% of respondents experience exhaustion only rarely and 3% not at all. Less than a half persons from control group (13%) chose the option „very often", the option „often" was chose by approximately the same number of respondents as caregivers (40%). By contrast „rarely" experience exhaustion 41% of persons and „not at all" 5% of respondents. It is necessary to highight the general purpose of this item. It is not possbile to measure the „intensity" of exhauation of individual persons this way. Even though – based on the general knowledge of strenuousness of homecare for a person with severe disability - it is possible to deduce that the intensive feeling of exhaustion stems from different causes and grounds in caregivers after all.[5]

Loss of the ability to enjoy free time of respondents
It is an item that measures impacts mainly of the long-term care when we talk about time demands as well as „physical and psychological" demands. Persons with severe disability very often require care that includes physically demanding tasks (getting dressed, hygiene etc.) or psychological power (stereotype, mental exhaustion from continuous responsibility etc.). After certain time caregivers state that even a short interruption of the strenuousness care does not bring the feeling of „regeneration", but only increases tension and exhaustion.
Statistically significant differences in answers of both groups were observed in this item. The option aften and very often was chosen by 62% of caregivers and „only" 32,5% from control group which means one half in comparison with caregivers! The same selection applies to options rarely and not at all (control group 66%, but caregivers 35%).

Feeling of losing personal prospects of respondents
The previous two items mapped the existence of negative „socio-psychological states and tuning" occuring at present – during assumed influence of the existing life model of respondents. The last item in the series of the so called negative losses of caregivers (both groups) is focused on perceiving and experiencing of the current „experience" of a caregiver projected to expectations towards the future.
The obtained data are very pesimistic – viewed by the eyes of caregivers. 22,2% stated that they have this feeling very often and another 31,5% experiences this feeling often. This feeling is rarely experienced by 27% of respondents and not at all only 15% of caregivers. Persons from the control group show quite different feelings. If the total of answers „often and very often" amounts to overall majority (53,5%) in the group of caregivers then the total of these answers in the control group is only 17,5%, which is only a third of the members of the basic researched group of caregivers! It is obvious that control group members are persons working on their personal development that should be confirmed by official authority in the near future. On the

[5] In another of our researches in 2007 we found out, that caregivers spent 15,54 hours caring a day (III. level of dependancy). And 18,24 hours at IV. level of dependancy on care. Every day, for the whole year. (Michalík, 2008).

contrary, caregivers see their future in the care for a ward that brings, nonetheless, monothematic and stereotypical activity. There is hardly ever hope for reaching a new – better condition.

Summary:

If we summarize the results of respondents' answers in this part of the questionnaire research that monitored opinions of respondents to the existence or development of the so called negative feelings and events concerning the long-term care as exhaustion, loss of the ability to enjoy free time, loss of the ability to rejoice, arrival of depression etc., then the following was found out: Caregivers showed in all items statistically much more significantly „negative" experiences and confirmed the existence of negative feelings and moods including negative expectations of the future development. They often in overall majority state that these negative feelings and states occur to them.

On the contrary, the control group members answered to all items almost „the other way round" (except for the questions focused on the feeling of exhaustion). It means that to questions focused on the existence or arrival of negative socio-psychological states in overall majority they chose rarely or not at all.

Results:

Tab. No. 6 Data's significance chart

Item	χ^2	SV	$\chi_{krit\ 0,05}$	Significance difference 0,05	$\chi_{krit\ 0,01}$	Significance difference 0,01
Massive arrival of depression and hopelessness	50,97075	3	7,814725	YES	11,34488	YES
Feeling of exhaustion	39,19546	3	7,814725	YES	11,34488	YES
Loss of the ability to enjoy free time	82,02452	3	7,814725	YES	11,34488	YES
Loss of personal life prospects	125,0099	3	7,814725	YES	11,34488	YES

CONCLUSION

The whole research, as well as this translated part, fully confirmed that there exist statistically significant differences in perception, assessment and experience of „aspects" of life that altogether form the so called its quality.

Due to the limiled extent it was not possible to publish all results, but we can confirm that also in other monitored areas and items such as:

a) assessment of changes during the care
b) relationship with broader social environment
c) partner relations
d) objective data bound with the quality of life
e) feeling of happiness and expectations to the future

caregivers showed diametrically different assessment of their own situation. Specifically, 47 cases were observed in 49 compared items when respondents from both groups answered differently and statistically significant differences on both levels of significance were obtained.

Thus, our research has confirmed the theory of the author of this article that talks about „alternative“ world of caregivers where their experiencing of a situation is diametrically different from the so called „common life of common family“. It is desirable that members of helping professions were introduced to these data and mainly were able to react to them.

LITERATURE:

1) BARNES, C., MERCER,G., SHAKESPEARE, T.: *Exploring Disability. A Sociological Introduction.* Cambridge: Polity Press, 1999.
2) EMERSON, E.; HATTON, C.; LLEWELLYN, G. et al. *Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities.* J Intellect Disabil Res. 2006 Dec; 50 (Pt 12): 862-73. Erratum in: J Intellect Disabil Res. 2007 Feb;51(Pt 2):172.
3) EMERSON, E.; MCCULLOCH, A.; GRAHAM, H.; et al. 2010. *Socioeconomic circumstances and risk of psychiatric disorders among parents of children with early cognitive delay. Am J Intellect Dev Disabil*. 2010 Jan; 115(1): 30 - 42.
4) FERNANDES J., SAUDUBRAY JM, VAN DEN BERGHE G., et al.: *Diagnosti. Inborn Metabolic Disease – Diagnosis and Treatment.* 4th edition. Springer, 2006.
5) GUGGENBÜHL-CRAIG, A.: *Nebezpečí moci v pomáhajících profesích.* Praha: Portál, 2007.
6) HATZMANN, J.; HEYMANS, H. S.; FERRER-I-CARBONELL, A.; et al. *Hidden consequences of success in pediatrics: parental health-related quality of life--results from the Care Project. Pediatrics.* 2008 Nov;122(5):e1030-8. Epub 2008 Oct 13.
7) HATZMANN, J.; VALSTAR, M. J.; BOSCH, A. M.; et al.: *Predicting health-related quality of life of parents of children with inherited metabolic diseases. Acta Paediatr.* 2009 Jul; 98 (7): 1205-10. Epub 2009 Apr 21.
8) KLASSEN, A. F.; MILLER, A.; FINE, S. 2004. *Health-related quality of life in children and adolescents who have a diagnosis of attention-deficit/hyperactivity disorder. Pediatrics.* Nov;114(5):e541-7.
9) MAREŠ, J. a kol. 2006. *Kvalita života u dětí a dospívajících I*. Brno: MSD, s. 6, ISBN: 80-86633-65-9.
10) MAREŠ, J. a kol. 2007. *Kvalita života u dětí a dospívajících II.* Brno: MSD, ISBN: 978-80-7392-008-1.
11) MICHALÍK, J. a kol. *Závěrečná zpráva z výzkumu „Postoje uživatelů sociálních služeb k novému způsobu jejich poskytování“*. Olomouc: IRVS, 2008.
12) MICHALÍK, J. Citizens with disability – Crisis of the Welfare State in Europe? In. Social Welfare: interdisciplinary Approach, Volume 2001 1(1), s. 8 – 15, Publishing House of Šiauliae University, LT-76285, Lithuania, ISSN 2029-7424.
13) MICHALÍK, J. a kol. Kvalita života osob pečujících o člena rodiny s těžkým zdravotním postižením, Vydavatelství UP, Olomouc, 2011. ISBN: 978-80-244-2957-1, 219 s.
14) MICHALÍK, J. *Poradenství uživatelům sociálních služeb, IV. upravené a doplněné vydání,* Praha: NRZP, 2009, ISBN: 978-80-87181-03-4.
15) READ, C. Y. The demands of biochemical genetic disorders: a survey of mothers of children with mitochondrial disease or phenylketonuria. J Pediatr Nurs. 2003 Jun;18(3):181-6.
16) SIEBERS, T.: *Disability Theory.* Michigan: The University of Michigan Press, 2008.
17) WAISBREN, S. E.; RONES, M.; READ, C. Y.; et al.: Brief report: Predictors of parenting stress among parents of children with biochemical genetic disorders. J Pediatr Psychol. 2004 Oct; 29 (7): 565-70.